

Ohio's  
Fetal Alcohol Spectrum Disorder  
State Steering Committee Plan:  
*Reducing the Prevalence & Incidence of FASD*

2009



Not  
a Single  
Drop

[www.NotASingleDrop.org](http://www.NotASingleDrop.org)

**Submitted by:**



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## **Ohio's FASD State Steering Committee Membership**

- Ohio Department of Aging
- Ohio Department of Alcohol and Drug Addiction Services
- Ohio Department of Health
- Ohio Department of Jobs and Family Services
- Ohio Department of Mental Health
- Ohio Department of Developmental Disabilities
- Ohio Department of Rehabilitation and Corrections
- Ohio Department of Youth Services
- Ohio Center for Autism and Low Incidence
- Ohio Family and Children First
- Double ARC
- The ARC of Ohio
- Parents/Caregivers
- Service Providers
- Ohio Resource Network
- Wright State University
- The Ohio State University Center for Learning Excellence

## **Ohio's Fetal Alcohol Spectrum Disorder (FASD) State Steering Committee Plan: Reducing the Prevalence and Incidence of FASD**

Since 2004, Ohio's FASD State Steering Committee has actively addressed the effects of FASD in Ohio. The partners in this effort included representatives of state agencies, parents and other youth and family serving organizations. The initial plan that guided the Steering Committee's work consisted of five major goals that focused on increasing the availability of services, providing education, developing screening procedures and enhancing data collection efforts. Review of the Steering Committee's past efforts indicated a variety of successful initiatives.

For example, the Steering Committee provided leadership and implemented a number of educational events including a state-wide social marketing campaign targeting physicians, educators and the general public. The "Not a Single Drop" web-site was launched and averaged more than 30,000 hits per month. Several training modules were developed and several summits and conferences were held. Based on past successes and a changing operational environment, Ohio's FASD State Steering Committee initiated a formal planning process beginning on November 21, 2008 in order to up-date the original state plan developed in 2004.

### **Environmental Scan**

At the initial planning meeting, significant attention was directed toward reviewing past efforts and completing a "scan" of the operational environment. The environmental scan focused on political, technological and other factors in the internal and external environments that were thought likely to impact the Steering Committee's ability to achieve strategic and long-term goals. Results of the environmental scan are indicated in Appendix A.

A general principle of the planning process utilized to support the development of Ohio's FASD State Steering Committee plan involved moving from general to more and more specific levels of analysis. The first and most general level of analysis involved identifying domains. Domains can be thought of as significant issues that Steering Committee members felt must be addressed to meet strategic and long-term goals. The second level of analysis focused on the development of several goal statements. Goals are broad statements of intended results. The third level of analysis resulted in the specification of strategies and actions.

### **Domains Guiding the Planning Process**

Analysis of the current operational environment resulted in the identification of four domains. The data that supported the identification of domains are indicated in Appendix A. Domains included:

1. Prevention of alcohol exposed pregnancies
2. Diagnosis and screening for FASD
3. Awareness and availability of services
4. Advocacy and services integration

## **Ohio's FASD State Steering Committee Goals**

The goals indicated below were developed by Steering Committee members through review and discussion of the domains referenced in the previous section of this report. In addition, goals evolved based on discussion of lessons learned through implementation of the initial FASD plan. Information that supported the development of goal statements is summarized in Appendix B. Specific goals of the Ohio's FASD State Steering Committee included:

1. Knowledge and understanding of FASD are enhanced among the general population and key constituencies.
2. The stigma associated with FASD is reduced.
3. The incidence and prevalence of FASD are reduced.
4. Referrals to appropriate services are increased when FASD is suspected.
5. Effective and comprehensive services are provided to care-givers and individuals with FASD with a special emphasis on opportunities for social development.
6. Parents/caregivers and individuals with FASD are helped.

## **Pathways to Achieve Steering Committee Goals**

Ohio's FASD State Steering Committee used the "logic model" as a format for developing their 2009 plan. The logic model is a device that allows planners to render a plan in graphic form and to specify linkages between actions and short- and long-term goals. In subsequent steps, specific outcomes and necessary actions can be developed that provide a basis for achieving goals. Ohio's FASD State Steering Committee designated two overarching strategies based on analysis of information and prior steps in the planning process. These strategies were labeled "Prevention of FASD" and "Treatment of FASD." Separate logic models were developed for each overarching strategy (see Appendix C and D).

### **Prevention Strategy and Related Activities**

The prevention strategy encompasses a series of educational activities (see below) directed toward key stakeholders. These activities are designed to enhance the knowledge and understanding of the origin and effects of FASD. Logic suggests that as education and knowledge are enhanced, prevalence and incidence will be reduced. Similarly, as education and knowledge are enhanced, the stigma associated with FASD will be reduced. Specific activities that will be initiated by Ohio's FASD State Steering Committee to prevent FASD include:

1. Provide education and training for medical professionals and service providers
2. Provide education and training for systems level personnel
3. Provide education and training for providers of services for high risk groups
4. Provide education and training for the general population
5. Provide education and training for high risk populations

6. Use regional training centers as a mechanism for promoting educational and training activities

The relationships between prevention activities and desired results are illustrated in the logic model in Appendix C.

### **Treatment Strategy and Related Activities**

The treatment strategy encompasses a series of activities designed to produce or contribute to several desired results. The activities identified below are directed toward assuring that “referrals are made when FASD is suspected.” Specific activities that will be initiated by Ohio’s FASD State Steering Committee to promote referrals include:

1. Secure buy-in from primary care providers to screen for and diagnose FASD
2. Secure buy-in from specialists to screen for and diagnose FASD
3. Train service providers<sup>1</sup> through video taped trainings and other mechanisms

The treatment strategy indicates that two primary activities will be initiated that may contribute to the “provision of effective services.” These activities include:

1. Integrating FASD materials into existing training curricula
2. Providing technical assistance to providers regarding “best practices” for addressing FASD

“Ensuring that FASD services and resources are integrated into other initiatives” will be addressed by “development of a crosswalk linking national, state and regional efforts.” Such integration may, in turn, function to “maximize the use of existing and new FASD related services.” Finally as “use of services is maximized,” “individuals and care-givers should receive appropriate and effective services” which should result in “parents/care-givers and individuals with FASD being helped.” The relationships between treatment activities and desired results are illustrated in the logic model in Appendix D.

### **Specific Initiatives and Accountabilities**

The prevention and treatment components (see prevention and treatment logic models) of Ohio’s FASD State Steering Committee plan provides a basis for state agency and other personnel to define specific activities/projects that will be implemented in the next 12 to 18 months. Some examples of specific initiatives that will be implemented include:

- All agencies will sponsor formal education and/or training activities directed to staff and/or service providers.
- The Ohio Department of Alcohol and Drug Addiction Services (ODADAS) will provide leadership at the state and national levels. In addition, ODADAS will incorporate FASD related information into their behavioral health training module and data collection strategies.
- The Parent Network will refer parents to appropriate services.

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<sup>1</sup> Steering Committee members suggested that service providers should assist in developing trainings.

- The Ohio Department of Health will link their web-site to the FASD web-site and will incorporate information about FASD into agency marketing materials.
- The Center for Learning Excellence at Ohio State University will convene medical professionals who agree to serve as champions.
- The Ohio Department of Jobs and Family Services will feature FASD materials on their health and wellness web-site and provide introductory training to systems managers.
- Nationwide Children's Hospital will develop and submit a grant to investigate behavioral treatment strategies for preschoolers.
- Ohio Resource Network will manage the FASD web-site.

Steering Committee members designated these activities as high, moderate or low priority. Thus, if resources are not sufficient to implement all strategic initiatives, high priority activities will be addressed first. Priority is based on five criteria including the extent to which the activity is: 1) visible; 2) cost effective; 3) piggy-backs on existing efforts; 4) likely to produce meaningful results; and/or 5) leads directly to a reduction in prevalence and/or incidence of FASD.

### **New Strategic Initiatives**

Ohio's FASD State Steering Committee members noted four potential strategies that should be considered in 2009. These strategies in order of priority included:

1. **Legislative Actions.** This strategy might include developing a formal legislative plan identifying desired outcomes and associated activities. "Signage" was identified as a critical result of the legislative agenda. Finally, it was agreed that the Ohio Legislature should be briefed regarding the issue of FASD and the successes achieved by Ohio's FASD State Steering Committee.
2. **Enhancement of the Parent Network.** Several ideas regarding the enhancement of the Parent Network were generated by members of Ohio's FASD State Steering Committee. Potential activities included creating a non-profit parent organization and mimicking strategies employed by other advocacy groups. The activities adopted by parent organizations devoted to addressing autism were noted as being particularly relevant. Finally, it was suggested that the Parent Network might develop "service maps" designed to assist individuals in navigating through the various systems that offer services to youth and families.
3. **Working with Physicians.** Work with physicians included identifying and convening champions. Champions were defined as physicians who are willing to advocate with their peers to address specific FASD related issues. Developing a "speakers' bureau" was noted as a potential means of communicating with physicians. A second key strategy focused on identifying and disseminating diagnostic tools to physicians in Ohio.
4. **Communicating with Young People.** This initiative should focus on expanding electronic forms of communication to disseminate messages related to FASD prevention and treatment. Maintenance of the FASD web-site and use of tools such as "You-Tube," "Facebook" and webinars were identified as potential means of communicating with a younger audience.

## **Next Steps and Recommendations**

Review of Ohio's FASD State Steering Committee plan suggests four primary recommendations:

1. New strategies and initiatives should be guided by the development of specific action steps, accountabilities and target dates for completion of individual steps. A tool for developing action steps is included in Appendix F. Specification of action steps provides a means of managing toward implementation of a specific initiative.
2. New strategies and initiatives should include the identification of formal outcomes. A tool for identifying outcomes is included in Appendix G. Specification of outcomes provides a basis for meaningful evaluation and opportunities to manage toward desired results.
3. Similarly, on-going activities and specific initiatives should be specified in greater detail including the statement of formal outcomes. Managers should also develop formal implementation plans to assist in the management of on-going activities.
4. The degree to which new initiatives produce desired outcomes should be assessed in a formal evaluation process. Such data may provide opportunities to expand the effort to address FASD in Ohio.

# Appendix A: Environmental Scan Notes

## Successes

- Website. Other states have looked at our website for information and replication
- Regional meetings have generated needs and ideas for action
- Regional and county groups have spun off our initiative to do awareness and service coordination and are being funded with federal and local dollars (Butler & Montgomery)
- Help Me Grow is still a resource
- Push at the state level related to developmental screening (Autism, pediatricians identify earlier)
- Teleconference training for Healthcheck coordinators was helpful
- Ohio Connection for Children with Special Needs is operational
- Medicaid is considering FASD
- Birth defects registry is operational
- Genetics database is operational
- Governor proclamations for FASD
- Systems and entities have come to the table
- PSAs are on-going and have snowballed into local initiatives (billboard in Toledo)
- Awareness of information is available to more people through technology (website, uTube)
- Branding has been successful. The consistent look and message has been successful
- There is a significant commitment at the state level

## Opportunities

- Medicaid: education for providers and consumers
- Interested parents
- Technology (Facebook)
- Second generation social networking
- Emphasis on autism promotes developmental screenings
- Improved developmental screenings
- Allowed to work at state and regional levels
- Interest in issue
- MR/DD involvement (networking)
- Birth defect system and genetic database
- Connection with Ohio Coalition for Children with Disabilities
- Large number of professionals and parents to draw from
- Work with ODE and school districts
- Staff opportunities for connections across other areas
- Web-based prevention system
- Behavioral Health Module modifications that gathers data on the treatment side
- Connect to high profile initiatives (brain development, school drop-out and autism)
- Advocate on a national level
- Marketing issues and efforts
- Legislative agenda with physicians and local providing information
- Reach youth

## Issues

- Information needs to be available in a wide range of technologies (uTube is not accessible to everyone)
- The website needs to be continually updated
- There are fewer resources available. Need to tap into non-traditional resources and capitalize on other initiatives such as infant mortality and March of Dimes
- Eligibility for services is still hard to establish
- Consistency in diagnosing is still an issue
- Advocacy to include FASD into the DSM V
- Reluctance to giving a diagnosis
- Services are still not available or accessible enough
- Awareness of services needs improved



- What is the best way to talk to parents
- Adopt specific protocols
- Teleconference training for Healthcheck coordinators needs to be repeated because of turnover and new demands on time
- Service specific technical assistance such as how to incorporate FASD questions into social histories and pre-sentence investigations
- Core trainings such as get FASD integrated into Institute for Human Services
- Wrap-around concept
- Legislation for signage in establishments that serve alcohol
- Bring education to the table
- At-risk populations are a priority
- Teachers need resources. Efficiency at the school level is needed. Using in-services and ESCs

## **Challenges**

- Get recognized with already established priorities (not a separate initiative) such as in schools, the developmental screening/autism initiative, pediatric practices, family planning waiver, etc.
- Time and resources for individuals and agencies (lay-offs, positions not being filled, etc.)
- 114,000 people living with FASD but only 60,000 with Autism. How to get FASD as a priority for awareness of prevention and intervention. There is no high profile advocate. We need a champion in the state.
- Standardized diagnostic criteria and willingness to diagnose. Getting information to families (adoptive, foster and birth)
- Not enough availability to early intervention services (wait list and only once a month)
- Funding at all levels
- Stigma (preventable, guilt and shame around anything related to alcohol or substance use)
- Don't lose priority status as an important issue at the national and state levels

# **Appendix B: Ohio FASD Strategic Planning Goals**

## *Actions from Planning Meeting*

### **Reduce alcohol exposed pregnancies (Prevention)**

1. Information & Education (Through web-based tools, brochures and PSAs)
  - General population (website, materials, PSAs, signage)
  - High-risk populations
  - Providers
  - Systems
2. Training (Through prenatal tools and screening)
  - Information, training and tools are available for medical and other service providers
  - High-risk providers
3. Technical assistance (Through phone, email and face to face interactions)
  - Targeted technical assistance is available for specific service providers in how to implement best practices
4. Workforce Development
  - Medical schools, associations and other public health care providers integrate FASD specific information into their training curricula
5. Stigma associated with birth mothers is reduced to promote early intervention and treatment

### **Improve screening & diagnosis for FASD (Diagnosis & Screening)**

1. Awareness and training for all child serving professionals (early intervention and public health nurses, child protective services, etc.) on how to make referrals when FASD is suspected
  - Continue birth defects curriculum in Help Me Grow Institute
  - Identify service providers to receive training ( CPS, adoptive, foster, Head Start, Help Me grow) and include these groups in the planning for training
  - Videotape modified training for web-based viewing by other service providers
2. Buy-in from primary care providers to screen and refer
3. Buy-in from specialists to screen and diagnose

### **Increase the availability and awareness of services for those affected by FASD (Improving Services)**

1. Training is available for parents/caregivers, service workers and support staff on effects of FASD on individuals across the lifespan
  - Identify key person (Ed Riley) for training in layman's terms on brain damage/central nervous system effects from FASD
  - Produce training tools
  - Use tools to train trainers for professionals (Ideally: MR/DD & MH staff) and parents and other organizations
2. A diagnosis of FASD opens the door for existing services
3. Use of existing services is maximized through awareness
4. Opportunities for socialization are available through tapping into organizations such as religious affiliates for inclusion of children and adults with FASD
5. Parents/caregivers of children with FASD will say they are being helped

### **Maintain & enhance state and national collaboration and integration of the FASD initiative (Advocacy & Service Integration)**

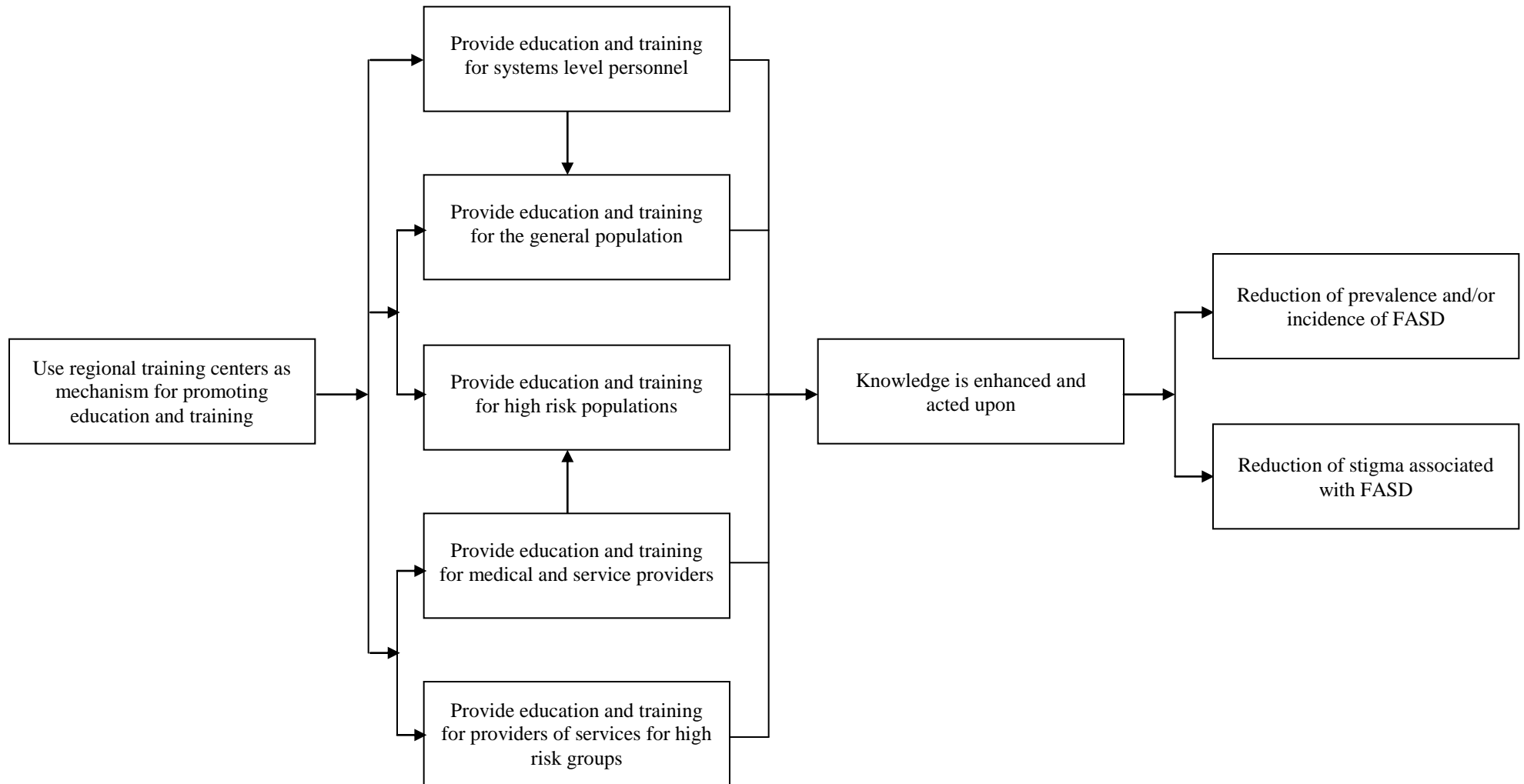
1. State and national key stakeholders are moved to action within systems
  - Increase relevance of FASD (Through developing a crosswalk of national, state and regional initiatives on FASD)
  - Utilize regional training centers
2. FASD is integrated into other initiatives
  - Linkages of systems/partners are identified through scopes of agendas and how FASD is a component

\*-Determine FAS prevalence and incidence in Ohio (**Data**)

\*-Demonstrate success across all goal areas (**Evaluation**)

\*-Reduce stigma regarding FASD (**Stigma**)

## Appendix C: FASD Prevention Logic Model (1/22/09)



## Appendix D: FASD Treatment Logic Model (1/22/09)

